

University of Dundee

Routinely collected infant feeding data

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1. Title

Routinely collected infant feeding data: time for global action in the era of big data

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Abstract = 39 words

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6. Conflict of Interest Statement

Catherine Chamberlain has used routinely collected perinatal data in research to improve maternal health outcomes.

Heather Whitford, Pat Hoddinott, and Lisa Amir have used routinely collected infant feeding data for infant feeding research.

Mary Renfrew has used routinely collected infant feeding data for infant feeding research and to inform policy development, and has been a collaborator on the UK Infant Feeding Survey.

Leanne Jones has completed a systematic review of breastfeeding outcomes reported in studies evaluating interventions used to support breastfeeding. Based on this we are preparing a global Delphi survey to reach consensus on the most appropriate and important core outcomes to women, clinicians and policy makers.

All authors are currently developing a recommended core-outcomes set for a Cochrane Generic Protocol for Cochrane Systematic Reviews of breastfeeding interventions.

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65 **7. Contributor statement**

66 All authors conceived the article. HW drafted the manuscript. All authors contributed to drafts.

67

68 **Title**

69 **Routinely collected infant feeding data: time for global action in the era of big data**

70

71 **Abstract**

72 This commentary sets out how routinely collected data, sometimes referred to as *Big Data* could

73 strengthen the global evidence and policy base, as has been demonstrated for smoking cessation.

74 An international collaborative effort is called for to progress this.

75

76 **Keywords**

77 Infant feeding; monitoring and evaluation; public health; breastfeeding

78

79 **Key Messages**

80 • International consensus on the collection and use of routine data for infant feeding is
81 currently lacking.

82 • The use of routine data has been shown to be a powerful tool for influencing policy, practice
83 and research in other areas of public health.

84 • The development of internationally agreed indicators and core outcomes and improved use
85 of routinely collected infant feeding data has the potential to re-invigorate global action on
86 breastfeeding.

87 **Main text**

88 Breastfeeding is important globally for healthy populations, with compelling evidence to support its

89 role in preventing the deaths of up to 823 000 children and 20 000 mothers each year (Rollins et al.,

2016). The 2016 *Lancet* series on breastfeeding has argued that global action to support breastfeeding has stalled and identified the lack of reliable standardised indicators as hindering effective progress (Victora et al., 2016). We argue that routine data and data linkage are crucial to inform global research and policy effectiveness (Jorm, 2015), but the collection and use of such data – both breastfeeding and the use of breast milk substitutes – lags well behind other health related behaviours like smoking. We outline the key issues affecting development of reliable infant feeding indicators and use of routine data that need to be addressed.

The power of routine data to re-invigorate global action has been demonstrated in the evaluation of tobacco policy on infant health in high income countries (Cox, Martens, Nemery, Vangronsveld, & Nawrot, 2013) and in evaluating infectious disease programs in low-middle income countries (Harries, Zachariah, & Maher, 2013). Large scale evaluations of natural experiments using routine data are valuable and often the only practicable means of evaluating the impact of complex systems interventions (Rutter et al., 2017) and changes in policies and services on population health (Ajetunmobi et al., 2013; Jorm, 2015). The collection and use of standardised data can also facilitate international research collaboration, enable effective data synthesis, and minimise research waste (Ioannidis et al., 2014). Although non-experimental analysis of routine data cannot determine cause and effect, it can contribute to knowledge and understanding that will advance infant feeding science.

Data on infant feeding practices and country specific policies are already gathered in over 70 countries worldwide (WBTi, 2017) as called for in the World Health Organization (WHO) Framework to increase breastfeeding (WHO/UNICEF, 2003). The World Breastfeeding Trends initiative (WBTi) compiles country-level data on national policies and indicators of infant feeding, including breastfeeding initiation and duration. National groups and/or core partners collect data within each country. This potentially offers global and national benchmarks for policy makers and enables inter-country comparisons on key indicators of practice, protection, support and promotion of

breastfeeding (WBTi, 2017). However, there are wide disparities in the types and methods of routine infant feeding data collected between countries (Rollins et al., 2016). There are also barriers for countries to overcome to set up systems, achieve effective access and use data to its full potential. Financial constraints and the relative priority given to WBTi data collection has affected the rigor or completeness. Most data are collected at routine health service attendances, thus the timing will be pragmatically chosen. Routine health care contact points differ between and within countries according to purpose, such as hospital discharge, child development checks, immunisation schedules, registration with a paediatrician, or collection of vitamins. Some countries only collect infant feeding data from periodic surveys – such as the National Health and Demographic Surveys in South East Asia (Dibley, Senarath, & Agho, 2010). Other countries have very limited systems in place for collecting routine infant feeding data, such as China and Russia (UNICEF, 2016).

Effective data use is affected by the level of detail collected. Understanding the differential impact of various infant feeding behaviours on health outcomes requires detailed measures including initiation and exclusivity of breastfeeding; whether the baby is breastfed or receives expressed breast milk by bottle/cup or other method; and whether expressed breast milk is fresh or frozen, mother's own or donor. However this detail is rarely recorded. Furthermore, data on the use of breast milk substitutes, such as infant formula brand, other liquids, and type, timing, and amount of solids used, are particularly poorly collected. The type of formula used is rarely if ever recorded, despite the fact that products differ across brand and over time, with differential impact on outcomes such as atopic disease (Renfrew et al., 2012). This seriously hinders the ability to answer important questions, such as the impact of not breastfeeding on the microbiome in different care contexts, the impact of breast milk substitute use on infectious diseases, the occurrence of cancer in women, or the effect on especially vulnerable infants such as those born preterm (Renfrew et al., 2012).

While some countries have relatively robust systems for the collection and analysis of routine infant feeding data, these can be adversely affected by policy changes or funding cuts. For example, Scotland was routinely collecting breastfeeding outcome data at six to eight weeks and eight months, at the start of the 'Breastfeeding in Groups (BIG)' trial (Hoddinott et al., 2009). However, halfway through the trial, the collection of eight-month routine data ceased, and a potentially important trial outcome – breastfeeding duration - could therefore not be reported. Systems and resources for storing, linking and analysing data are also variable. A recent Australian trial, Supporting breastfeeding In Local Communities (SILC), found that using routine infant feeding data as the primary outcome required time-consuming work to extract the data from individual council databases (McLachlan et al., 2016). Relevant data may be stored in the mother's maternity database (such as gestation at birth, or pregnancy complications) or the child's record, however the ability to link these datasets may be lacking. Requirements to collect core data in a standardised format and enable linkage would strengthen analyses of the relationships between infant feeding exposures and outcomes. One example might be the question of whether prematurity or the method of feeding affects infant health outcomes.

While the World Health Organization/UNICEF have suggested standardised methods of collecting infant feeding information, not all countries gather data in the same way. Published analyses are therefore "...based on a limited number countries, for a limited number of indicators, and a limited number of background characteristics" (UNICEF, 2016, p. 101). Analyses are generally not available for high-income countries, where breastfeeding rates are particularly low (Victora et al., 2016). Some indicators may need to be tailored to reflect the different epidemiological patterns of breastfeeding in different countries, for example measuring sales of formula in countries with very low breastfeeding rates (Baker et al., 2016).

The lack of an internationally agreed core outcome set for infant feeding limits opportunities to compare, contrast and combine data (WBTi, 2017; Williamson, Altman, Blazeby, Clarke, & Gargon,

2011). This deficiency poses a considerable challenge in finding reliable and complete data for international comparisons (Victora et al., 2016). Standardised routinely collected infant feeding data by country would require internationally agreed definitions and consistent timing of data collection. It could be used by researchers and policy-makers to guide selection of primary or secondary infant feeding outcomes for trials of new and complex interventions to improve breastfeeding outcomes, improve monitoring of usual care, or support the evaluation of policy and systems level changes (for example Hoddinott et al., 2009; Nickel et al., 2017; Relton et al., 2018). This alignment would enable the use of more practicable and sophisticated strategies to evaluate complex breastfeeding interventions, for example comparing infant feeding rates and outcomes between populations over time. Nesting trials within large cohorts with linked data offers opportunities for efficiency. Evolving synthesis methods such as network meta-analysis offer increased opportunities to demonstrate relative benefits in the future. However these opportunities can only be realised if the data are available and accurate.

There are relevant lessons from the successes in other fields of public health such as smoking. For example fluctuating daily smoking and e-cigarette behaviours present similar data collection challenges to variations in mixed feeding with breast milk, formula and other liquids. In the 1990s, Professor Lumley demonstrated the value of strong health outcome data for leveraging commitment to reduce smoking during pregnancy (Lumley, Oliver, & Waters, 1999). Observational evidence of infant health outcomes among women who smoke is limited due to very serious concerns about confounding. Lumley et al (1999) conducted a meta-analysis of maternal and infant health outcomes from trials enrolling women who smoked during pregnancy, who had been randomised to a smoking cessation intervention or control. The findings clearly illustrated not only a reduction in smoking in late pregnancy but importantly, a significant reduction in preterm births and low birth weight among infants of women receiving smoking cessation interventions (Lumley et al., 1999). This seminal Cochrane systematic review, and its subsequent updates, have been fundamental in demonstrating the health benefits and direct health system cost savings from investments in

smoking cessation interventions, estimated to be in excess of 500 million pounds per annum in the UK alone (Taylor, 2009). It did not answer every question about outcomes of smoking in pregnancy, but established a platform for further refinement and exploration of the data.

We argue that international agreement to develop reliable indicators and improved use of routinely collected infant feeding data are needed to re-invigorate and evaluate global action on breastfeeding. There is an urgent need to reach consensus on recognised, standardised definitions in every country. As a preliminary step, development of a core outcome set for a Cochrane Generic Protocol for Cochrane Systematic Reviews of breastfeeding interventions is in progress. Our team has completed a scoping review of breastfeeding outcomes reported in studies evaluating interventions used to support breastfeeding (publication pending). This is informing a global Delphi survey to reach consensus on the most appropriate and important core outcomes identified and prioritised by parents, clinicians, experts and policy makers. In addition, strategic investment is needed to develop robust and reliable data collection methods, governance policies to protect individual privacy, and secure electronic linkage systems to improve overall efficiency.

We call on governments, global and national decision makers and researchers for genuine commitment to engage in efforts to develop reliable and agreed core infant feeding indicators and harness the power of large routinely-collected data. This has the potential to reinvigorate coordinated global action on breastfeeding so that the important public health benefits can be realised.

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